



# **Report on the Administration of the Protection and Advocacy and Client Assistance Programs**

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**Commission on Quality of Care &  
Advocacy for Persons with Disabilities**

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Governor**

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## **SUMMARY**

This report examines the administration of the federal protection and advocacy (P&A) and client assistance (CAP) programs. The Commission on Quality of Care and Advocacy for Persons with Disabilities (CQC) conducted an internal review of these programs and, in July 2011, the U.S. Department of Health and Human Services, Administration on Developmental Disabilities, conducted a site visit of the New York State P&A program for persons with developmental disabilities. Both the review and site visit identified deficiencies in New York's P&A/CAP programs which must be addressed.

To chart a path forward, CQC conducted public forums throughout the state and received written comments through its website, a dedicated email address, and by mail. In addition, CQC convened a series of discussions with national experts on P&A and CAP programs.

CQC's review of its P&A/CAP programs shows a fundamental conflict between the mission of CQC and its federal P&A/CAP programs. As a state agency, CQC cannot bring litigation or engage in independent legislative advocacy, two core activities of the federal P&A/CAP system. In light of this historical conflict, CQC contracted with independent nonprofit organizations to provide these services. However, given CQC's role in state government, CQC cannot provide central coordination of litigation or legislative activities. To improve the P&A/CAP system, CQC recommends that the Governor designate a nonprofit organization to serve as the P&A/CAP agency in New York.

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## **A. CQC's Mission and Responsibilities**

The Commission on Quality of Care and Advocacy for Persons with Disabilities (CQC) was established in 1977 as part of New York's comprehensive reforms implemented in the wake of the Willowbrook scandal to provide oversight of the quality of care provided to persons with developmental disabilities, mental illness, and substance abuse disorders. As defined by state law, CQC's oversight mission has two principal components: (1) to investigate and report upon issues concerning quality of care and (2) to advise and assist the Governor in developing policies, plans, and programs for persons with disabilities. Over time, that oversight mission has expanded to include residents of adult homes with mental illness and inmates of state correctional facilities with mental illness. In 2005, the functions of the Office of the Advocate for Persons with Disabilities were merged into CQC and CQC's responsibilities were expanded to include advocacy on behalf of all persons with disabilities.

## **B. The Federal Protection and Advocacy and Client Assistance Programs**

The federal protection and advocacy (P&A) system was created to provide federal oversight of each state's systems of care for persons with disabilities. The P&A program consists of seven programs:

- Protection and Advocacy for Persons with Developmental Disabilities
- Protection and Advocacy for Individuals with Mental Illness
- Protection and Advocacy for Individual Rights
- Protection and Advocacy for Assistive Technology
- Protection and Advocacy for Beneficiaries of Social Security
- Protection and Advocacy for Individuals with Traumatic Brain Injury; and
- Protection and Advocacy for Voting Accessibility.<sup>1</sup>

Under federal law, each state's governor designates a single state or nonprofit agency to serve as the state's P&A. The designated P&A administers each of the seven P&A programs.

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<sup>1</sup> Protection and Advocacy for Persons with Developmental Disabilities, 42 U.S.C. §15041 *et seq.*, 45 C.F.R. 1386.1 *et seq.*; Protection and Advocacy for Individuals with Mental Illness, 42 U.S.C. §10801 *et seq.*, 42 C.F.R. 51.1 *et seq.*; Protection and Advocacy for Individual Rights, 29 U.S.C. §794e, 34 C.F.R. 381.1 *et seq.*; Protection and Advocacy for Assistive Technology, 29 U.S.C. §3004; Protection and Advocacy Beneficiaries of Social Security, 42 U.S.C. §1320b-21; Protection and Advocacy for Individuals with Traumatic Brain Injury, 42 U.S.C. §300d-53; Protection and Advocacy for Voting Accessibility, 42 U.S.C. §15461.

The federal government has also established the Client Assistance Program (CAP) to assist individuals with disabilities in accessing vocational rehabilitation services.<sup>2</sup> The CAP may be administered by an agency separate from the agency administering the P&A programs. However, the majority of states, including New York, house their CAP within the same agency as the designated P&A.

A state's governor may redesignate its P&A or CAP agency for good cause.

### **C. New York's Protection and Advocacy and Client Assistance Programs**

In 1980, CQC became the designated federal protection and advocacy agency in New York and, in 1984, the designated CAP agency. When it became the P&A/CAP, CQC contracted with nonprofit organizations to provide P&A/CAP services.

P&A/CAP contractors provide invaluable assistance to New Yorkers with disabilities including information and referral, technical assistance, training and education, individual advocacy, and systemic advocacy. Through this work, P&A/CAP contractors positively impact the lives of countless New Yorkers.

CQC currently administers 8 P&A/CAP grants through 41 contracts with 18 contractors.<sup>3</sup> The chart below shows each contractor, the grants those contractors receive, and the total amount of P&A/CAP grant funding each contractor receives.

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<sup>2</sup> Client Assistance Program, 29 U.S.C. §732, 34 C.F.R. 370.1 *et seq.*

<sup>3</sup> The number of contractors recently declined from 20 to 18 due to the expiration of certain contracts.

<b>Contractor Name</b>	<b>Grants</b>	<b>Amount</b>
<b>New York Lawyers for the Public Interest</b>	Developmental Disabilities Mental Illness Individual Rights Beneficiaries of Social Security CAP (Legal) <sup>4</sup>	\$708,022
<b>Legal Services of Central New York</b>	Developmental Disabilities Mental Illness Individual Rights Beneficiaries of Social Security Traumatic Brain Injury CAP (Legal)	\$528,406
<b>Disability Advocates, Inc.</b>	Developmental Disabilities <sup>5</sup> Mental Illness Individual Rights Beneficiaries of Social Security CAP (Legal)	\$493,322
<b>Neighborhood Legal Services, Inc.</b>	Developmental Disabilities Mental Illness Individual Rights Beneficiaries of Social Security Assistive Technology CAP (Legal)	\$429,000
<b>Nassau/Suffolk Law Services</b>	Developmental Disabilities Individual Rights	\$256,800
<b>Center for the Independence of the Disabled NY</b>	Voting Accessibility CAP (Advocacy)	\$224,943
<b>Legal Services of the Hudson Valley</b>	Developmental Disabilities Individual Rights	\$175,400
<b>Albany Law School</b>	Developmental Disabilities	\$133,900
<b>Legal Aid Society of NNY</b>	Developmental Disabilities Mental Illness	\$119,700
<b>Western NY Advocacy for the Developmentally Disabled</b>	Developmental Disabilities	\$117,600
<b>Catskill Center for Independence</b>	Voting Accessibility	\$105,343
<b>Touro College of Law</b>	Mental Illness	\$87,500
<b>Resource Center for Independent Living</b>	CAP (Advocacy)	\$77,800
<b>Long Island Advocacy Center</b>	CAP (Advocacy & Legal)	\$73,500
<b>Capital District Center for Independence</b>	CAP (Advocacy)	\$46,300

<sup>4</sup> Client Assistance Program grants are divided between legal and non-legal advocacy and housed, with one exception, in separate organizations. Organizations providing legal advocacy are noted as CAP (Legal), non-legal advocacy as CAP (Advocacy), and both as CAP (Advocacy and Legal).

<sup>5</sup> Disability Advocates, Inc., also receives a sub-contract from Albany Law School in the amount of \$74,885 to provide assistance to individuals with development disabilities. The sub-contract amount is included in the Albany Law School total.

<b>Westchester Independent Living Center</b>	CAP (Advocacy)	\$45,800
<b>Regional Center for Independent Living</b>	CAP (Advocacy)	\$42,900
<b>Western NY Independent Living</b>	CAP (Advocacy)	\$39,800

Depending on their contracts, some contractors provide a full range of services. Others focus their efforts on a more limited set of services providing, for example, individual advocacy and training, but no systemic advocacy.

The types of services the contractors provide are further defined by the nature of the contracting organizations. CQC has P&A/CAP contracts with legal services organizations, independent living centers, and law schools. Depending on their sources of funding, these entities may have restrictions on the types of activities they may pursue with the P&A/CAP grants received. For example, an organization that receives funding from the federal Legal Services Corporation (LSC) is prohibited, among other things, from pursuing class action litigation or litigation on behalf of persons who are incarcerated in local jails or state prisons, 45 C.F.R. §§ 1637.2, 1637.3. These restrictions apply to the entire organization receiving LSC funds and therefore limit the types of litigation or administrative remedies an LSC-funded entity may pursue with P&A or CAP funds. A chart with the types of contractors is below:

<b>Type of Contractor</b>	<b>Number of Contractors</b>
Independent Living Center	7
LSC-funded Legal Services Organization	5
Non-LSC funded Legal Services Organization	4
Law School	2

The geographic areas covered by the grants also vary. For example the P&A grant to serve persons with developmental disabilities divides the state into eight regions, the grant for persons with mental illness into six regions, and the grant for beneficiaries of social security into four regions. The grants to support individuals with traumatic brain injuries and to provide access to assistive technology are made to a single contractor. As a result, counties can have from four to seven P&A/CAP contractors, as summarized in the chart below:

<b>Number of Contractors</b>	<b>Counties</b>
<b>Counties with 4 Contractors (22 total)</b>	<i>Bronx, Broome, Cayuga, Chemung, Chenango, Cortland, Delaware, Herkimer, Jefferson, Kings, Lewis, Madison, New York, Oneida, Onondaga, Oswego, Otsego, Queens, Richland, Rockland, Schuyler, Tioga</i>
<b>Counties with 5 Contractors (16 total)</b>	<i>Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Livingston, Monroe, Niagara, Ontario, Orleans, Seneca, Steuben, Tompkins, Wayne, Wyoming, Yates</i>
<b>Counties with 6 Contractors (21 total)</b>	<i>Albany, Clinton, Columbia, Dutchess, Essex, Franklin, Fulton, Greene, Hamilton, Montgomery, Orange, Putnam, Rensselaer, St. Lawrence, Saratoga, Schenectady, Schoharie, Sullivan, Ulster, Warren, Washington</i>
<b>Counties with 7 Contractors (3 total)</b>	<i>Nassau, Suffolk, Westchester</i>

#### **D. Federal Administration on Developmental Disabilities Site Review**

In April 2011, the Administration on Developmental Disabilities (ADD) notified CQC of its intention to review CQC's administration of its Protection and Advocacy for Persons with Developmental Disabilities program and, in July 2011, conducted a three-day site review.<sup>6</sup> In December 2011, ADD issued a findings letter in which ADD identified several areas of concern, summarized below.

First, ADD questioned CQC's independence from New York State agencies providing treatment and services to individuals with developmental disabilities due to the gubernatorial appointment of CQC's Chair and Commissioners and the CQC Chair and CQC staff reporting to members of the Governor's office.

Second, ADD criticized CQC's contracting, finding that CQC fails to engage in a meaningful priority-setting or outreach process. As a result, CQC's contractors have wide discretion to focus on client work within each contractor's own priorities and to establish their own intake protocols which may not be consistent with statewide goals or priorities. Relatedly, ADD criticized the failure to engage CQC's Advisory Council in developing these goals and priorities.

Last, ADD sought additional budget documents to demonstrate that CQC and its contractors spend federal P&A funds in a manner consistent with federal law. Such documents have subsequently been made available to ADD.

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<sup>6</sup> Five federal agencies administer the Protection and Advocacy and Client Assistance Programs. The Protection and Advocacy for Persons with Developmental Disabilities (PADD) program is administered by the Administration on Developmental Disabilities (ADD), located within the Administration for Children Youth and Families at the U.S. Department of Health and Human Services. ADD's site review applied only to CQC's PADD program.



## **E. Public Consultation**

In January 2012, following its internal review and the ADD site review, CQC initiated a period of public consultation, conducting public forums throughout the State and receiving written comments through its website, a dedicated email address, and by mail. CQC sought input on the following questions:

1. What constitutes an effective P&A/CAP program?
2. What successes and challenges have you encountered while working with New York's P&A/CAP programs?
3. Would the P&A/CAP programs be better served by a not-for-profit agency administering New York's P&A/CAP programs?
  - a. What are the potential effects on service delivery, including client service and access to resources?
  - b. What are the organizational advantages and disadvantages that might result from transition to a not-for-profit agency?

Over 100 people responded to CQC's request for comment. Participants included persons who had received services through the P&A/CAP system, current providers of P&A/CAP services, consumer and provider associations, and other stakeholders.

The most consistent theme among the comments received was the excellent services provided by current contractors. Some individuals described training or information that empowered them to advocate for themselves. Others described assistance they or their loved one received to access appropriate care, secure an appropriate education, access vocational services, or combat discrimination. Others described systemic reform efforts, including litigation to allow individuals with mental illness in adult homes to reside in the community and to reform the state's correctional mental health system.

Some participants spoke of the advantages of locating P&A/CAP services in organizations that provide other services. Thus, independent living centers providing CAP advocacy services spoke of other support or advocacy services a person with a disability would also be able to access at such a center. Organizations providing legal services spoke of their ability to cross-refer within the organization if an individual needed other legal services. One organization that works with private law firms spoke of its ability to refer matters to private law firms that provide free legal assistance to individuals with disabilities. Several organizations spoke of the

additional resources they have available to assist individuals with disabilities through additional fundraising.

The majority of comments did not address CQC's administration of the P&A/CAP system. Of the comments that did, the most frequent comment was that the P&A/CAP system ought to be led and staffed by persons with disabilities. Disability leadership and employment was described as the best way to ensure that the P&A/CAP is responsive to the concerns and priorities of people with disabilities and that P&A/CAP will be free from physical and attitudinal barriers towards people with disabilities.

A local presence was also highly valued. Due to the size of New York State and the unique needs of each community, a number of participants recommended that the P&A/CAP maintain regional offices throughout the State, employing individuals with deep knowledge about the local community.

Participants also described the wide range of services that the P&A/CAP should provide. These services include information and referral, training, education, individual advocacy, and systemic advocacy. Several participants observed that under the current P&A/CAP system, it is difficult for people with disabilities to know where to go when they need help. Others argued that a weakness of the current system is that CQC, as a state agency, does not coordinate systemic litigation or legislative advocacy.

Only a few participants addressed the question of whether the P&A/CAP system should be moved to a nonprofit agency. Those who addressed the question supported the move, describing the benefits as increasing P&A/CAP independence, eliminating unnecessary administrative costs and a corresponding increase in resources for advocacy staff, and establishing statewide policies and priorities that would best advance the interests of people with disabilities. Several participants cautioned that any change to the current system ought to be done deliberately, in a manner that engages disability stakeholders and preserves the strengths of the current system.

#### **F. National Protection and Advocacy and Client Assistance Program Practices**

In addition to seeking public input, CQC convened a series of discussions with national experts on P&A and CAP programs. CQC focused on recent trends in P&A/CAP administration, the practices of other large state P&A and CAP programs, and national standards recently developed by the national membership organization of P&A/CAP organizations, the National Disability Rights Network (NDRN).

## 1. Trends in P&A/CAP Administration

Most P&As are housed in private, nonprofit agencies. Of 57 state and territorial P&As, 47 are housed in nonprofit agencies, 9 are in state or territorial agencies, and 1 is housed in a state university.<sup>7</sup> Thirty-three state P&As also administer the CAP program. Of the 9 state or territorial P&A agencies, CQC is the only one that discharges its responsibilities primarily through contracts with nonprofit organizations.

The trend has been to move state or territorial P&A agencies out of state government. New Jersey and North Carolina have recently moved state agency P&As to nonprofit organizations. Ohio is in the process of doing so and Virginia recently initiated a process to privatize its P&A/CAP.

The reasons states have privatized their P&As have varied, but the most common reason has been to ensure the independence and autonomy of the P&A. In addition, states have moved their P&A/CAP function to a nonprofit to assure the P&A/CAP flexibility to comply with federal funding rules without state law restrictions on budget, hiring, or travel.

The table below shows the ten largest P&A/CAPs in the country, the amount of funding the P&A/CAP received in federal fiscal year 2010-11, and whether the P&A/CAP is public or private.

State	Amount	Public or Private
California	\$11,067,892	Private
Texas	\$7,695,156	Private
New York	\$6,112,940	Public
Florida	\$5,845,635	Private
Pennsylvania	\$4,238,337	Private
Illinois	\$4,115,594	Private
Ohio	\$4,018,067	Public <i>transitioning to Private</i>
Michigan	\$3,553,094	Private
Georgia	\$3,300,248	Private
North Carolina	\$3,239,508	Private

<sup>7</sup> Connecticut, Indiana, Kentucky, New York, North Dakota, Ohio, Virginia, American Samoa, and Puerto Rico have state/territorial agency P&As, although Ohio and Virginia are transitioning from a state agency to a not-for-profit agency. Alabama's P&A is part of the Alabama State University School of Law.

## **2. Other Large State Protection & Advocacy/Client Assistance Programs**

CQC examined the practices of the two largest P&A/CAPs, California and Texas.<sup>8</sup> Each serves a large state with a geographically, racially, ethnically, and linguistically diverse population. To meet the challenge of serving a large state, both California and Texas have regional offices throughout each state. California is organized into five regional offices with patients' rights advocates located at each of its five state psychiatric hospitals. Texas has twelve offices, of which six are regional offices that offer a full suite of services and six offer more limited services. In addition, Texas organizes its staff into statewide issue teams, with members of the teams dispersed throughout its offices.

The California and Texas P&A/CAPs are led by individuals with disabilities, with the majority of board members being either people with disabilities or their family members. California and Texas also employ people with disabilities and people representative of the racial and ethnic populations in each state.

Both California and Texas P&A/CAPs conduct broad outreach and engage stakeholders in developing statewide goals and objectives for their programs. This engagement includes regional focus groups, public forums, and broadly disseminating surveys to persons with disabilities and other stakeholders. The boards of each agency, which are led by persons with disabilities, review and approve plans developed through this process.

California and Texas have each engaged in major systems advocacy in recent years. Texas led efforts to reform that state's juvenile justice system. California has successfully fought proposed cuts to Medicaid-funded services for persons with disabilities.

## **3. National P&A/CAP Standards**

CQC reviewed the standards developed by the National Disability Rights Network (NDRN), the national association of P&A/CAP agencies, and adopted by a consensus vote of P&A/CAP executive directors in October 2011. These standards reflect the generally accepted norms for an effective P&A/CAP system.

The NDRN Standards provide that P&A/CAP management should be independent from agencies providing services and structured to support effective legal and rights advocacy. The board and advisory councils should be led by individuals with disabilities and represent the

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<sup>8</sup> The Texas P&A has administered the Texas CAP program since 1984. California's CAP program is housed within the California Department of Rehabilitation, which subcontracts with the California P&A.

cultural, ethnic, racial, and disability diversity in its state. The P&A should hire, retain, and promote persons with disabilities.

The standards further state that the P&A/CAP should have a process for identifying and adopting annual priorities through stakeholder and public input. These goals and objectives help determine the individual legal and lay advocacy provided to persons with disabilities, as well as the systemic advocacy that will be undertaken. The board and council should participate in the development of and adopt the annual priorities established through this process.

According to the standards, a P&A/CAP agency should ensure that its services are made available throughout the state. To accomplish this aim, the P&A/CAP should conduct outreach and training, and establish a presence in targeted facilities and settings where persons with disabilities live, work, or receive services.

The NDRN Standards identify systems advocacy as a core function that should be a significant component of each P&A/CAP's activities, including bringing impact litigation and affecting state or federal legislative action.

### **RECOMMENDATION**

#### **The P&A/CAP System Would Be Improved by the Governor's Designation of a Nonprofit Organization to Serve as the P&A/CAP Agency**

Based upon its review of the P&A/CAP system, CQC believes that the P&A/CAP system would be improved by the Governor's designation of a nonprofit organization as the P&A/CAP agency.

A nonprofit organization would be better able to centrally coordinate functions and knit together the disparate strands of work currently performed by CQC's contractors, including the coordination of legislative advocacy or litigation. The nonprofit model would also bring New York's P&A/CAP system in line with the vast majority of states which have designated nonprofits to serve as the P&A/CAP agency.

The move to a nonprofit agency should seek to preserve the excellent work currently performed by P&A/CAP contractors. CQC's P&A/CAP programs have assisted tens of thousands of New Yorkers with disabilities over the past 31 years. Individuals with disabilities and their family members who spoke at the public forums and shared written comments eloquently described the profound changes in their lives and the lives of their loved ones brought about by the P&A/CAP system.

CQC therefore recommends that any newly designated P&A/CAP organization should continue contracting with existing P&A/CAP contractors for a defined period of time. During this time, a newly-designated nonprofit would evaluate whether to continue these contracts or establish regional offices of a single, statewide nonprofit. In making this determination, the nonprofit organization should examine to what degree existing contracts allow for consistent and coordinated services. If the organization chooses to deliver services through regional offices, these offices could employ the individuals currently performing work under P&A/CAP contracts, assuring continuity of service.

In structuring its services, a newly-designated P&A/CAP should look to the expressed desires of New York's disability community, the experience of other large state P&A/CAPs, and national standards. The nonprofit organization should be led by individuals with disabilities, with the majority of board members being either people with disabilities or their family members. It should employ people with disabilities and people representative of New York's diverse racial, ethnic, and linguistic communities. It should engage in broad stakeholder outreach to develop its priorities. The nonprofit should seek to deliver a consistent and coordinated set of services responsive to the needs of New Yorkers with disabilities.

Through these reforms, CQC believes that the strengths of the current P&A/CAP system will be preserved through a structure that supports consistent and coordinated P&A/CAP services throughout the state. This reformed system will provide the best possible protection and advocacy for New Yorkers with disabilities.